HOUSE OF COMMONS

Work and Pensions Committee

Oral evidence: Disability employment gap, HC 957

Wednesday 28 April 2021

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Watch the meeting

Members present: Stephen Timms (Chair); Debbie Abrahams; Siobhan Baillie; Steve McCabe; Nigel Mills; Selaine Saxby; Dr Ben Spencer; Chris Stephens; Sir Desmond Swayne.

Questions 158 - 201

Witnesses

I: Rob Geaney, Head of Campaigns and Public Affairs, RNID; Martin Sigsworth, Senior Employment Manager, Thomas Pocklington Trust; and Daniel Jennings, Senior Policy and Campaigns Officer, Epilepsy Action.

II: Sarah Rawlings, Executive Director of Research, MS Society; Catherine Hale, Founder and Director, Chronic Illness Inclusion Project; and Professor Karen Walker-Bone, Director of the National Centre for Musculoskeletal Health and Work, Versus Arthritis.

Rob Geaney

DEG0120 Royal National Institute for Deaf People

Daniel Jennings

DEG 110 Epilepsy Trust

Sarah Rawlings

DEG 0150 MS Society

Professor Karen Walker-Bone

DEG 0179 Versus Arthritis at Southampton University

Catherine Hale

DEG 0151 Chronic Illness Inclusion Project

Examination of witnesses

Witnesses: Rob Geaney, Martin Sigsworth and Daniel Jennings.

Q158 **Chair:** Welcome, everybody, to this meeting of the Work and Pensions Select Committee and a warm welcome and thanks to our witnesses, who have joined us for both the panels that we are looking forward to taking evidence from this morning. Can I ask the members of the first panel to very briefly introduce yourselves to us, starting with Rob Geaney?

Rob Geaney: Hi, good morning. My name is Rob Geaney. I am Head of Campaigns and Public Affairs at the Royal National Institute for Deaf People, the RNID.

Martin Sigsworth: Hi there. Yes, I am Martin Sigsworth. I am the Senior Employment Manager at Thomas Pocklington Trust and we work with blind and partially sighted people.

Daniel Jennings: Good morning. I am Daniel Jennings, Senior Policy and Campaigns Officer at Epilepsy Action.

Q159 **Chair:** Thank you all for being with us. Can I put two questions to each of you? I will give you both of them and ask you all to comment on both of them. First of all, do you think the disability employment gap is a useful measure or do you think there is something more useful that we should be looking at?

Secondly, do you think employers should be required to report how many disabled people they employ and how much they are paid? Would you like to see that being an obligation on employers? Can I ask you each to comment on both of those points, starting with Rob Geaney?

Rob Geaney: We definitely value the overall disability employment target and we welcome the fact that it has been committed to by the Government. I certainly think reducing the disability employment gap has the potential to really benefit individual lives, but also change society's attitudes towards disability and make sure that disability is visible and accepted in the workplace. I think it is a necessary target, but I agree that it is potentially not sufficient. We know from our survey work around half of the people with hearing loss feel that their careers have been limited because of their hearing loss, so—as well as this binary focus on in and out of work—there is possibly value in more subtle and complex data around career progression, pay gaps and other issues.

On mandatory reporting, we are sympathetic and see why it would be a useful tool to have. The only thing that makes us slightly nervous is that, because hearing loss is a hidden disability, we know that lots of people do not disclose their hearing loss to their employer. We think that roughly half of people with hearing loss do not provide that information at the recruitment stage. A similar proportion again will not tell their employer about their hearing loss, often because they think they will be judged as unable to perform their job or because they just do not think any reasonable adjustments will be made and, therefore, they do not see the purpose and the value of going through that process.

I think, before we get to the point where mandatory reporting has real value, we need to identify some of the ways we can increase the reporting and disclosure of disability in hearing loss to make sure that that mandatory reporting has value and it does not create false information.

Martin Sigsworth: At Thomas Pocklington Trust we completely support the target of reducing the disability employment gap. We believe it is too high. What we would particularly like to see is a further breakdown into the representation of different disabilities. For example, research within the sight loss sector suggests that 75% of blind and partially sighted people are currently out of work, which is quite a lot higher than that of the general disability public, if that makes sense.

It is Government and people and employers being aware that there is an existing disability employment gap, but that gap is a lot wider for blind and partially sighted people. We feel it is very important and should be noted. Yes, as I say, we do support it but some further breakdown of different disability types would be very beneficial as well for us. That would enable us to see themes and identify groups that may be even more underrepresented within the workplace.

In terms of mandatory reporting, similar to what Rob just said, we do have some reporting, particularly from partially sighted people, who are able to get by without telling their employers that they have a disability. There is certainly a reluctance with people to tell their employer that and they will try to get by, so again the data might not be as accurate. However, saying that, anecdotally what we hear from a lot of blind and partially sighted people is that they would like to know which employers do employ disabled people and are walking the walk, so to speak.

In that regard, as an organisation that is working with people to find them employment, it would be handy if we had reporting that told us, "These employers do employ disabled people and have a good record. This is how many they employ" and it gives us that evidence to confidently direct people to those kinds of employers.

Daniel Jennings: I would echo a lot of what Rob and Martin have just said. From the ONS figures, we know that only 34% of people with epilepsy are in employment. Again, that is a lot lower than other disability groups. On top of that, research by the TUC has pointed out that, on average, people with epilepsy are paid 11.8% less than non-disabled workers. People with epilepsy find it more difficult to get into work and when they are in work they are paid less than other workers are. We would definitely support both targets to reduce the disability employment gap, but also mandatory reporting, both on the disability employment gap and the disability pay gap. I think that would help.

Again, I would echo what the previous witnesses have said about reporting further on specific impairment groups as well, so we can identify themes and particular trouble areas, and provide targeted support to those groups that we can see are then having more problems getting into the employment market.

Q160 **Nigel Mills:** Can I ask the panel if they could outline what they think the main barriers to employment are that the people they are supporting face in trying to get into work or sustain that work?

Daniel Jennings: All of our survey research on this has shown that the biggest barriers faced by people who are deaf or have hearing loss tends to be employer attitudes. It is not that employers do not want to do the right thing, but I think often they struggle to find the information and resources. People think that hearing loss is not well understood in the workplace or more widely across society.

As I think I outlined in our written evidence, we have done some research on this that showed that 35% of business leaders would not know how to communicate with somebody with hearing loss. Around a quarter thought that deaf people were a health and safety risk, which is obviously a complete myth. We also know that the majority of employers do not know where to go to get help and information and advice. I think that all builds up to a point where employers, often who want to do the right thing and want to support disabled members of staff, do not know how to. That creates barriers in the workplace.

I also think it is very important to think not just about barriers in getting into work, but we know that people with hearing loss and lots of other disabled people are far more likely to leave the labour market, particularly people with hearing loss take early retirement. As well as thinking about barriers to the employment market, it is also important to think about barriers within them so that people do not drop out prematurely.

Nigel Mills: Thank you. Martin, any thoughts on this?

Martin Sigsworth: Yes, absolutely. Following on from what Rob just said, employer attitudes are a big barrier that a lot of blind and partially sighted people report to us and report to our employment advisers. They feel that they have gone for roles and not got them on the grounds of being blind or partially sighted and the employer not being confident about being able to support them within that role. It is quite hard for them then to bring any action against that, even when it is quite clear.

Another major barrier is inaccessible recruitment processes for blind and partially sighted people, particularly as more application forms move online. We are seeing that there are a lot of inaccessible application forms online, which blind and partially sighted people struggle to access because it doesn’t work very well with their assistive technology. When it comes to filling out the form to even be considered for the job, they are struggling at that stage, which makes it impossible for them to then get an interview.

Finally, confidence and competence using the assistive technology that they need for the workplace. Currently, there is no clear provision of support to train blind and partially sighted people to use the assistive technology that they need to be able to access the labour market. For example, if somebody with a degenerative eye condition loses their sight in their 40s, there is no support if they are out of work to show them how to use the assistive technology that they will need to be able to re-enter the labour market.

This is a big problem that is faced by blind and partially sighted people, because it is a big piece of technology that people need to be able to use and need to be able to use competently to be able to succeed in the workplace. If they are not getting the training to use it, it can be a problem. Then they enter work and the employer is not able to support them with it and the employer cannot wait for them to get the training to become competent to be able to do that job, so it is a bit of a vicious circle.

Nigel Mills: Thank you. Daniel, any comments?

Daniel Jennings: Yes. Similarly, one of the main barriers is a lack of understanding from employers. We understand that, as a fluctuating and invisible condition, epilepsy can be quite difficult to understand but, just by undertaking some quite simple training of the sort of that Epilepsy Action provides, employers and co-workers can understand how to help and support people with epilepsy more in the workplace. We know from our experience that that can make a huge difference, but at the moment there is just a lack of understanding and still quite a lot of discrimination and stigma against people with epilepsy.

We know from our research that over a quarter of UK employers would be wary of working with someone with epilepsy and a majority of UK employers would not know how to help someone when they were having a seizure. Again, undertaking some quite simple training can help dispel this discrimination and lack of understanding and just make the workplace a more confident and comfortable place for people with epilepsy.

Q161 **Nigel Mills:** Thank you. I think you have said previously that people with epilepsy have one of the lowest employment rates among disabled people, down as low as 30%. Do you have a feeling as to why this is when you might assume that a fluctuating condition perhaps will be in a better position than one that does not fluctuate?

Daniel Jennings: Again, it is mainly a lack of understanding. As I think Rob and Martin have both previously mentioned, a lot of people with epilepsy, partly with past experiences, are unwilling to disclose their epilepsy at application stage. Once they do disclose their epilepsy, a lot of people have had past experiences where they are side-lined in the workplace because of this lack of understanding. Past experiences can go a long way to affecting the mental health of people with epilepsy. That then has a knock-on effect on their confidence and willingness to apply for jobs going forward. What we have seen is a focus on what people with epilepsy cannot do in the workplace as opposed to what they can do in the workplace. Challenging and improving some of those employer attitudes would go a long, long way to making people with epilepsy more confident in applying for higher jobs as well.

Another issue is job retention. When a worker is diagnosed with epilepsy some employers are great and they can put support in place quite quickly, but others, once a diagnosis is revealed, are quite quick to side-line people with epilepsy. I think more needs to be done looking at job retention as well and keeping people in the job market once they are in.

Q162 **Debbie Abrahams:** Good morning, everyone. I want to follow up on Nigel's questions. We are going to have various specific questions on different policy measures over the next half an hour or so. If you were starting from scratch, if you had a blank sheet of paper, what would you want to see in terms of the policy measures that would address the barriers that you have identified?

Daniel Jennings: Again, looking at job retention, there are not enough schemes at the moment to keep people in work. Access to Work is great when it works, but it is one of the only schemes out there looking at job retention, so I think more schemes keeping people in the job market once they are in would be invaluable. One of the main things we would want to see as well is more disabled people involved in these reforms. All too often we do not see that kind of engagement with disabled people in designing systems that work for them, so as far as possible involving disabled people in reforms and decision-making would go a long, long way to better understanding how we can help them.

Another issue is that a lot of the support out there is far too generic. There are a lot of programmes out there, but there is not enough focused support. Going back to mandatory reporting, if we could understand the different impairment groups and where that support is needed, and then focus that support on those groups, that would go a long way as well.

Martin Sigsworth: Again, similar to what Dan has just said, I think a more tailored approach for support for different types of disabilities is going to be very important. One thing that we have noticed in delivering the support that we do to blind and partially sighted people is that not everybody needs the same level of support. Somebody might just need somebody to check the format in an application form before they submit it, whereas someone else might need help to understand how to complete an application form, and those are two very different cases.

We would also like to see much more support put in place for blind and partially sighted people to understand the assistive technology that is available to them in the workplace, and training to be provided on how they can use that, so that when they do get roles they can hit the ground running and are not relying on Access to Work to provide that training to them, where usually in the first three to six months of their role an employer is waiting for them to be able to use assistive technology effectively. That again is going to increase job retention.

Yes, I would say those are the two main areas, more training around assistive technology and around bespoke support for blind and partially sighted people.

Rob Geaney: Again, I am going to largely agree with my fellow witnesses, particularly Martin’s point about user involvement in designing policies. We see the DWP is very good sometimes at engaging with DPOs, disabled charities and disabled people, around relatively small-scale issues, so reasonable adjustments but not necessarily the side of the big-issue policies.

It is very hard to say what the one silver bullet in all of this is. One of the frustrations we have is that some of the simple, easy bits of low-hanging fruit out there, the Government have not taken them on. We have all talked so far about employer attitudes being a big problem. That does not stem from employers not wanting to do the right thing and not having the good intentions, but there just isn’t the advice, the support and the guidance out there for them to do so.

We have been arguing now for a couple of years that the Government should create an online employer information hub, which is well advertised, contains lots of information around employment disability law, guides on individual conditions, signposting to other organisations and just very simple steps to help make reasonable adjustments. I know a website is not that easy, but it does not seem like an incredibly difficult thing to do, therefore we are not quite sure why the Government have not taken that small step, which just addresses the barriers that all of us have identified. If I had to pick one thing, it would be that creation of an employers’ information hub, where employers can get the knowledge and reassurance they need to be able to do the right thing, as they want to do.

Debbie Abrahams: Fantastic, some very tangible examples. Thank you so much, everyone.

Q163 **Sir Desmond Swayne:** In January, the *Journal of Public Health* noted that working-age adults with a disability had been disproportionately financially affected by the pandemic. Intuitively, I would have thought that homeworking and reliance on technology would have favoured adults with disabilities, but clearly the reports are that they have worked fewer hours on the job retention scheme furlough. What do you anticipate will happen at the end of furlough in respect of their employment and why do you think they have been disproportionately affected?

Rob Geaney: One of the key things that is often overlooked with this is the digital skills and the digital access that disabled people have. I think Ofcom has research that shows that 95% of households have internet access. That drops to something like 67% for deaf people and I think it is 65% for disabled people overall. Therefore, those extra costs of the pandemic and those extra barriers to work for some disabled and deaf people have existed because of that online access.

It is very difficult to say what will happen to disability employment after the pandemic. As a charity, we are certainly concerned that the pandemic has thrown up new barriers in the way of disabled people and their employment chances. For deaf people, the use of face coverings in the workplace, partitions and rearranging office spacing so that people are encouraged to sit back to back all makes life harder for deaf people, who rely on lip reading or other forms of communication support.

I do not think employers have been given enough information to understand and respond to those barriers. If some of those things are with us in the long term, unless they are addressed and unless employers are given guidance on how to make new reasonable adjustments because of Covid measures, we may well see more deaf people discriminated against and finding life in the workplace harder.

Martin Sigsworth: One of the things that has been reported by people accessing the Thomas Pocklington Trust's employment services, when it comes to homeworking, has been the platforms that employers are using to facilitate that homeworking. These are not always compatible with the screen reader and magnification software that people are using. On paper, for a blind or partially sighted person, more home working is generally favourable because it cuts out the need to travel, which can obviously be a cause of anxiety for people and a cause of difficulty. If the platforms that employers are using to facilitate homeworking are not accessible with the assistive technology that that individual is using, that means that they are unable to work as efficiently as if they had been in the office.

Another issue that we had, particularly in the early days, was access to support workers. That was due to people not being able to have their support worker come to the home due to the regulations that were in place around social distancing and people visiting your home. If the support worker was not a part of the family, particularly at the start, it was difficult for them to be able to do some of the tasks that they would have relied on the support worker to do while they would have been in the office.

Looking at the longer term, one of the great things has been how Access to Work has brought in a blended approach. We would like to see that continue, so support for blind and partially sighted individuals when they have to go into the office and also when they have to work from home has been very positive. That is probably the main thing for us.

Daniel Jennings: From our point of view, the pandemic has very much been a mixed bag for people with epilepsy. Where people can work from home it has been massively beneficial. Again, with people not having to travel to work, that takes out a big stress of the possibility of experiencing a seizure in public. Generally speaking, we know that disabled people are more likely to be working in frontline services, so their experiences have been worsened during the pandemic. The added stress of the possibility of having a seizure and ending up in hospital during Covid is massive for people with epilepsy. We know that stress is one of the main triggers for seizures.

Going forward, we are concerned that—again, looking at employer attitudes—people with disabilities are likely to be the ones let go first, and furlough has added a massive financial stress to people with epilepsy, which again leads to them having more seizures. It is very much a mixed bag. Where people can work from home, I think hopefully that will continue going forward but it creates more stress, so it is very much a mixed bag.

Q164 **Selaine Saxby:** Good morning, everyone. Do you think that the employment support programmes that the DWP has introduced during the pandemic—such as Kickstart and Restart—will provide the support that disabled people need to move into work?

Daniel Jennings: The short answer is no. Both programmes are quite generic. They are not targeted enough at disabled people. One of the main issues that has been raised with Epilepsy Action about both schemes is that you need to be on Universal Credit to access them, but we are aware of many people still on Employment Support Allowance who cannot access these schemes, so it is not helping them to start moving into work.

Rob Geaney: I would mainly echo what Daniel said about the generic nature of many of these provisions. We know from the services we provide that specialist support with an understanding of deafness, and particularly for first language BSL users, is instrumental in the success of those employment schemes. The schemes the Government have created in response to the pandemic have been very generic.

Selaine Saxby: Thank you. Martin, do you have anything you would like to add?

Martin Sigsworth: I have nothing to add that the guys have not already said. Well, just one thing to add: blind and partially sighted people that we have been working with, when we have suggested these schemes, there has certainly been a lot of anxiety from our clients about applying for them because they have been let down by these sorts of schemes before. They do not feel that they have the unique kind of support that a blind and partially sighted person will need within that workplace and even through the recruitment stage as well.

Q165 **Steve McCabe:** I want to ask about your experience of the Work and Health Programme in particular. We have heard evidence from a number of sources that it is not that effective when it comes to disabled people. I think the Spinal Muscular Atrophy UK group say that eight in 10 disabled people did not achieve a defined job outcome under the programme. The Centre for Social Justice Disability Commission said that only 14% of disabled people who took part moved into employment as a result. What is your own experience of the Work and Health Programme and indeed some of the other programmes, but that in particular?

Rob Geaney: From our perspective, we have delivered employment services through a range of different funding schemes. We have found that some of the other schemes potentially allow us to do more for those that are slightly further away from the labour market. For some deaf people—particularly BSL users—it is a long time before they can get to even employment-related activities. Before you get to that stage there may be a housing issue, a social care issue or a benefits issue. It may be a couple of months working with the individual before we can even get to the point where we are talking about the activities they need to move into work.

The Work and Health Programme, because of some of the limits on how long individuals can be on that scheme and because of the fact that essentially the payment by results mechanism is so blunt around finding work, it is difficult for providers to invest in those furthest from the labour market. More flexible schemes that allow us to work with individuals for longer, which recognise that taking steps to get closer to the labour market without moving into the labour market are incredibly important, allows us to provide better support in different types of schemes.

Martin Sigsworth: With the Thomas Pocklington Trust employment support we are self-funded, so we are not relying on any Government contracts or any funding. What we have noticed is that, when we are engaged with people that have been delivering the Work and Health Programme, as soon as they get a blind or partially sighted person, they are quite keen to pass them over to us, rather than work with them themselves because of the specialist support that we can offer. That is all well and good but, equally, it does mean that, if we do not operate in an area where somebody lives and is accessing that Work and Health Programme, we are not sure what support they are getting.

We also have not had many, if any, examples come through where a blind or partially sighted person has gone through the Work and Health Programme and succeeded and ended up working. I am not sure it is working for blind and partially sighted people, from what I can tell.

Daniel Jennings: I would echo what Rob and Martin have said. We have not had many examples—if any at all—of people who have been successful through the Work and Health Programme. Generally speaking, the most damning indictment of all the programmes available is that the disability employment gap has remained stable for a long time now. It is clear that, while there are a lot of programmes out there, they are not having the impact that is needed to close the disability employment gap.

Q166 **Steve McCabe:** Thank you. Rob, could I ask you in particular about Jobcentre Plus staff? I read quite a damning account from RNID about Jobcentre Plus staff insisting that someone must use the phone in order to raise their issue. What is your experience of trying to deal with Jobcentre Plus staff?

Rob Geaney: It is incredibly mixed, if we are being honest. There is some brilliant practice out there. I have been to some Jobcentres and they have shown us the measures they put in, but it does appear to be a bit of luck for the individual and whether their Jobcentre has done the things they need to do. One of the things that I think has seen a slight improvement—but we are not there yet—is the way that an individual's communication preferences are recorded within their Universal Credit journal. That is a step forward, but we want to see the Jobcentres think more systematically about how they capture and implement a user's communication preferences.

The NHS has a model called the Accessible Information Standard, where, as I say, the communication preference is held on a patient record and then the support and the adjustments they need, in theory, should follow them around the NHS. We would like to see a model very close to that potentially brought in for Jobcentres: an automated process where the communication support needs are captured and then it is automatically provided as that person moves around the system.

Q167 **Steve McCabe:** That would be one very practical measure that could be implemented. Thank you. Martin, I notice that Thomas Pocklington has called for better training for Jobcentre Plus staff. What do you have in mind, what training in particular?

Martin Sigsworth: It is more training around understanding sight loss in particular and the support that somebody might need. A lot of people that access our service describe having problems getting to Jobcentre Plus, getting around Jobcentre Plus, people not really knowing how to guide them properly or the support that they might need. You might arrive at the Jobcentre and you clearly need support to get to where you need to go, but they might be left standing outside or might be left standing inside.

Similar to what Rob said, partners of TPT—particularly in London and previously in Birmingham—have done work with Jobcentre Plus and they are open to this training, but it is very reliant on organisations going to them directly to offer it, rather than it being anything that staff members get as mandatory training when they are working in a Jobcentre Plus environment. General visual awareness training for any blind or partially sighted person that is arriving at that centre would be very beneficial. I think that would alleviate a lot of the anxieties that blind and partially sighted people have when they attend the Jobcentre Plus.

Q168 **Steve McCabe:** Thank you. Daniel, I noticed that Epilepsy Action has called for more disability employment advisers. The Department say it is going to employ another 315. Does that mean you are satisfied? Do you think that is the job done?

Daniel Jennings: No, I don't think so. We would want to see more than the stated number so far. We would need to see how that worked in practice. Ideally, we want to see job coaches with a specific understanding of specific conditions to target that support, so someone with epilepsy should be seeing a job coach who has an understanding of the condition and the barriers to employment so they can work on a more individual basis to help the individual and address the specific problems that they have.

Q169 **Steve McCabe:** How many more than 315 would you say are needed?

Daniel Jennings: It is difficult to know and put a number on it. We would need to see how it worked in practice. Ideally we want specific training for people, for the job coaches to understand epilepsy. In a perfect world, we would want to see every Jobcentre have a specific epilepsy job coach who understood epilepsy and that replicated across all the disabilities. That might be a bit of a pipe dream, but in an ideal world that is something that we would want to see.

Q170 **Steve McCabe:** So you could not put a figure on that at the moment. Finally, as I am conscious of time, the Department ended the Community Partners Scheme in April 2019. When I asked the Department about this, it said that it wasn't that great a loss because it has been subsumed within other activities. How significant was that scheme and do you think it has been a loss or have you noticed it? I think that is for everyone, but quickly.

Rob Geaney: We are aware that some areas of the Community Partners Scheme did have an impact, but it seems to be a role that was not particularly well defined. It was very much on individual Jobcentres or regions of Jobcentres to define the purpose of that role. It comes back to the point that Martin and Daniel have already made, where, whether or not the Community Partners Scheme stays, it is part of a bigger question about the training that is provided to work coaches and the specialist support that they have to access. I would not necessarily fixate on community partners individually, but the whole package of support and training as a whole, which at the moment is not meeting the needs of deaf people in the Jobcentres.

Martin Sigsworth: I would second that. The Community Partners Scheme was very hit and miss. From reporting from sector partners, I believe it worked fairly well in the north-east. That was because organisations had been quite active in building those relationships up and that had worked. However, in other areas it had a minimal effect.

Generally, an overhaul of the support that is provided to disabled people within Jobcentre settings is more important than reinstating the

Community Partners Scheme, with a greater understanding of different disabilities and the support needs that those individuals have. The support is quite generic, particularly what blind and partially sighted people receive at the moment. Therefore, we need a greater focus on providing tailored support for somebody with a disability and for these coaches to have some expertise. It doesn't need to be just a job coach that can specialise for a blind or partially sighted person. Rather than coaches being expected to support every single type of disability that walks through the door, there could be two or three specialists who can work on it.

Steve McCabe: So not a great loss then. Is that your view as well, Daniel?

Daniel Jennings: Yes, I would echo what Rob and Martin have said. It was very much a postcode lottery and, from our experience, we did not see that it had much of an impact on our cohort of people.

Q171 **Chair:** One argument that has been put to us is that local commissioning for employment support for disabled people would work better than national commissioning. Do you think local commissioning would work better?

Martin Sigsworth: It obviously would depend on how you are defining local and what the remit of that would be because, for blind and partially sighted people, it would very much depend on where they had to attend and things like that. "Local" can mean the north-east of England, so would somebody in Middlesbrough be able to get to somewhere in Newcastle? That is going to be extremely difficult. It would depend on where the support was being delivered from and what was defined as "local", because mobility and transport is an issue for blind and partially sighted people.

In terms of understanding the labour market in those regions, that would definitely be a positive. What we have noticed with the delivery that we do working with blind and partially sighted people in London, compared to somebody that is in Liverpool or Manchester, the landscape is very different and the challenges are very different, particularly around public transport and being able to access public transport and also the job opportunities that are there.

I would say that there are some benefits, but it would depend on how tailored it was towards different types of disability and making sure that the support that those individuals are getting is going to work for them. It does not matter whether it is local or national. If it is not tailored to the needs of a blind and partially sighted person or is not accessible to them, it does not matter where you deliver it. It needs to be right for the individual.

Daniel Jennings: I would echo a lot of what Martin said. There are positives and negatives to support locally. Local support would be better able to identify employers in the local area that have a good track record, but you do risk a postcode lottery of some support in some areas being better than in others. It would need a strong national framework for it to work properly locally and to make sure provision was fair across the board, so that some areas were not benefiting more than others.

Ideally, yes, local support would be fantastic and you could build up support with local employers, but we do not want to run the risk of a postcode lottery and some people being disadvantaged in that system.

Rob Geaney: I agree with a lot of what has already been said. There are benefits to local, but the key concern for us has always been specialist compared to generic, rather than local versus national. It is the ability to deliver specialist services that understand specific conditions. RNID is a supplier of employment support and where we have been able to deliver projects over quite large regions they have been sustainable and they have been deliverable.

In the past, because we deliver specialist services, we have been asked to register with individual Jobcentres almost on the basis of, "If we have somebody who can come to you—" and we have been unable to do that, purely because of the time and the effort and because it is not sustainable for us to deliver a service for a small number of people in an area. It is sustainable for us to deliver a service for a slightly larger group over a larger area. While I see the benefits of local over national, at RNID we are far more interested in specialist over generic as the big factor in what makes a difference.

Q172 **Chris Stephens:** I think Rob has answered some of my questions when he answered Debbie Abraham's questions, so I am going to ask Martin and Daniel first, but I will maybe ask Rob to emphasise these points. Martin and Daniel, thinking back to my time as a trade union representative—which was not that long ago—and having heard the evidence we have heard so far in this inquiry, we are getting evidence that some employers and some managers have a basic lack of understanding of reasonable adjustments and how to implement them. Is that a view that you both share and do you have a specific example or a striking example that you would want to give to the Committee? Martin first.

Martin Sigsworth: Yes, there is definitely a lack of knowledge around reasonable adjustments for blind and partially sighted people. It could be as simple as colour contrasting on a keyboard or on a till or something like that. It is the unknown for a lot of managers. That does not mean that once you engage with them that they are not open to it, but a lot of the time it is the individual with the disability or with the visual impairment in our case that has to know the solution. They do not always know that.

One example that I can give was from a couple of years ago. We worked with an individual who got a job at Sainsbury's. He had disclosed his disability but was unable to do certain tasks on the shop floor as quickly as his colleagues. The way that he could speed that up was by using a handheld magnifier. However, his line manager was saying that he could not use it because it did not look professional and he stopped him from using it. It was the same with operating the till. He was slower than his colleagues because he was not able to use his handheld magnifier.

Fortunately, this individual had contacted us and told us about the problems and we were able to advise him. This was the day before a disciplinary meeting, where he was due to lose his job because his performance was not up to scratch. The reason his performance was not up to scratch was because he had been denied using the technology that he needed to be able to perform the job well.

We got involved. We spoke to Sainsbury's HR department and highlighted what was going on. That disciplinary meeting was cancelled and rearranged. There was a different meeting that took place with a different member of the HR team and the line manager. It was all explained, the support was put in place and three months later, when I caught up with the individual, he was absolutely flying and was going for a store manager role.

It is clear that, if a line manager is unwilling or unaware of the support that an individual needs and denies him use of that technology, it can really impact people being able to retain their employment and then progress within their employment as well.

Chris Stephens: Thanks, Martin, that is a very striking example.

Daniel Jennings: Unfortunately, we have heard of a lot of examples where employers were unwilling to make reasonable adjustments for whatever reason. One of the main concerns we have had is a lot of our stories have come from within the NHS itself. That is massively concerning when you consider that the NHS should be one of the employers that understands disability better than others.

We have had a lot of examples of people, once they start having seizures, being moved from live services to other areas of the business and they feel side-lined. Reasonable adjustments for people with epilepsy are fairly minimal and involve things as simple as providing a rest area for people, once they have had a seizure, or more flexible working hours if people are more likely to have seizures early in the morning. Being a bit more flexible and changing work hours can help massively, but unfortunately we hear all too often the reluctance of employers to make even simple changes.

We have good examples of the difference that those adjustments can make. We have worked with a lot of employers locally and nationally to provide training on epilepsy. When they undertake that training and understand the condition a bit more, and how minimal those reasonable adjustments are, that makes a huge difference and employers are more likely to implement those reasonable adjustments if they have a little bit of training from ourselves.

Q173 **Chris Stephens:** Thanks, Daniel. Having represented workers with epilepsy and trying to explain to managers what needs to be done around reasonable adjustments, I fully agree with what you are saying.

Rob, you have given some excellent suggestions there about what the Government could do. My question to you is: what needs to be done to ensure that the part of the Equality Act that covers reasonable adjustments is suitably enforced? Because there is an enforcement issue, isn't there?

Rob Geaney: There is absolutely an enforcement issue. I think the vagueness and the fuzziness of reasonable adjustments is part of the enforcement problem. I do not think that deaf people understand where the line is and how far they can push an employer.

I will give one example of enforcement that illustrates just how bad it is at times. We are aware of a lot of people who are given an assessment by Access to Work. That may include an employer cost-share or before Access to Work steps in that an employer make certain reasonable adjustments. We do get a lot of people who have had that assessment. Their employer had been given those recommendations and they just refuse to do it. Even when Access to Work says, "This is a reasonable adjustment" or, "This is the cost-share you should make" an employer will say no, and if they do say no they seem to be able to do it with impunity.

That individual cannot change their employer. They are not given recourse and Access to Work will not enforce it. It might be a relatively small group of people that that affects, but is an illustration of just how easy it is for employers to abdicate their responsibility. It is quite a powerful example.

Q174 **Chris Stephens:** Indeed, Rob. Again, it has taken me back to my trade union past a few years ago. Martin and Daniel, is there anything you would want to say to the Committee in relation to how we can enforce the Equality Act, particularly in relation to reasonable adjustments?

Daniel Jennings: One of the key issues we would like to see is giving employees confidence to know when they are being discriminated against. Our research has identified that a lot of people do not know where the line is, in terms of discrimination, and do not have the confidence to challenge their employers when they are being discriminated against.

In terms of reasonable adjustments, one simple thing we would like to see is the introduction of timescales, so putting the pressure on employers to provide a timescale for when those reasonable adjustments will be implemented. Far too often we see long delays that then cause frustration for the employee and it feels like they are being forced out of the business in a backhanded way.

Martin Sigsworth: The main area where we see issues is around reasonable adjustments. Where we would like to see greater support for the individual would be when they are looking at retaining their employment, so when they have a degenerative eye condition and they have previously been working in the role but the employer is not willing to make the adjustments to enable them to retain that employment where it is possible.

It is very difficult for somebody who has recently lost their sight to understand what reasonable is, and then, when they feel that they are not being treated fairly, to bring any kind of action against their employer. It is such a complicated and overwhelming process for somebody to do that. It is something that, as an organisation, we struggle with as well: how can we challenge more employers when we know that they are not doing what they should be doing under the Equality Act?

Q175 **Chris Stephens:** My next question is: how effective is Access to Work in retaining people in work and getting people into work?

Rob Geaney: We sometimes overlook just how transformative Access to Work has been. We have talked to British Sign Languagers—a slightly older generation than myself—and they saw their working opportunities completely limited often to the low end of the labour market, so it has completely transformed some people's ability to do their jobs and to have a career and to have aspirations. Therefore, I do not think that we should lose sight of the good stuff within Access to Work.

We have a lot of concerns and we get a lot of inquiries and evidence that too often the system just does not work as it is supposed to. I have already mentioned the problem with reasonable adjustments and how Access to Work recommendations do not have to be implemented by employers. Time and time again we find that advisers do not necessarily understand the disability or the solutions they are proposing for people.

A big one for us is the compatibility of assistive technology. Access to Work will make recommendations around a piece of equipment without any knowledge of whether it is compatible with the office equipment the individual uses, and, for our beneficiaries, whether it is compatible with their hearing aids. Often they get given a piece of equipment that is worthless.

The big key here is about empowering the disabled person and the deaf person to co-design their package of support. People know the support they use. They know the support they can access in many cases and they should be empowered to do that, but often Access to Work tells them the support they need. Indeed, within the guidance that advisers and assessors get, they are told not to pay too much preference to the individual's needs and wants. That is completely contrary to the design of good disability policy. It should be a co-production where the individual is allowed to understand and communicate the support they get in the workplace.

Q176 **Chris Stephens:** Martin, I think Rob has a point. Isn't the biggest challenge here with Access to Work that employers sometimes ignore the recommendations from Access to Work or there is reluctance to put the funding in that Access to Work is asking an employer to do?

Martin Sigsworth: I would say that, for blind and partially sighted people, it is getting the right assessment and right advice for the equipment that they need to be able to do the job.

At Thomas Pocklington Trust, we run an internship programme where we offer entry-level roles specifically to blind and partially sighted people. I get involved in the Access to Work process quite a lot with those individuals. It is amazing, the lack of knowledge that turns up when the assessment is being done.

Our interns are often inexperienced within the workplace. They do not necessarily know the equipment that they are going to need. Fortunately they have me on hand. I am an experienced member of staff who has worked in the sight loss sector. I also have a visual impairment and so am able to help them through that. If they were placed in an organisation that did not have that specialism, that individual would be really struggling and the assessor would not be able to help them.

An employer might be willing to put in the money but then the equipment turns up and it does not work with their systems or it is not right for that individual. Then you have a hell of a job to go back and say, "We need this. We did not need that" because the assessment has been done. You have signed it off in good faith as you think that an expert has turned up and done that assessment and that it is right.

I would say it is more specialism in the assessors that are working with these individuals. You can fight to get a specialist company to come and do your assessment for you if you are blind and partially sighted, but that is a hell of a battle and it is not something that is offered as standard for any blind or partially sighted person.

I would also like to see—it is something that Access to Work is looking into—a kind of passport, so that when you move from job to job there is an acceptance that there will be certain pieces of equipment, which as a blind or partially sighted person you are going to need, no matter the job that you do.

As a blind person, I know that I could leave TPT tomorrow and go and work for another organisation. I am going to need text to speech software and Access to Work should know that, because I have spent the last 15 years working and I have always needed that. I would have to do another assessment and put in another claim, which could take up to three months to get that piece of equipment to start the new job.

If there was a passport in place where I could just go, "Look, you know that I have had this before. I am still blind. Can we just sign this off immediately, I can get it and then I can hit the ground running with my employer?" that is going to be very beneficial as well. The assessment processes and how you then have to navigate Access to Work as an individual, once you have had an initial assessment done and subsequently moving on to roles, is more important to the individual. That is a bigger issue than employers not implementing the recommendations that have been made, because I do not have an awful lot of evidence to back that up for blind and partially sighted people.

Q177 **Chris Stephens:** Thanks, Martin. That is very comprehensive. Before I pass back to the Chair, Daniel, do you have anything on Access to Work and its effectiveness?

Daniel Jennings: Generally speaking, Access to Work is a fantastic scheme, but there are some issues that people with epilepsy have experienced, particularly delays in getting reasonable adjustments implemented. We have heard of delays of six to nine months to get those reasonable adjustments in place. That causes frustration for both the employer and the employee and can lead to a further breakdown in that relationship.

Another issue that we want to have looked at, in terms of Access to Work, is making it available during the job search as well. That would help disabled people get into work and make sure that those reasonable adjustments are in place once they start their employment as well.

Q178 **Dr Spencer:** You have spoken a lot about the need to educate and support employers. Isn't this what the Disability Confident scheme is about and how do you think that is working?

Rob Geaney: We have always appreciated the intention of the Disability Confident scheme and we see what it is trying to achieve, but I do not think there is enough within that scheme to make it achieve what it wants to do. If you look at the steps for employers, especially at the three bands, so those that are committed, they do not need to do anything. They just need to sign up and say that they will do something in the future and it gives that false impression.

There is no information provision within Disability Confident. I have mentioned before the case of the employment gap, which just isn't there. Even the DWP's own research, when it evaluated the scheme—I think the last time it did this was in 2018—showed that the biggest action those organisations that had signed up to Disability Confident were doing was to promote that they were a Disability Confident organisation.

Other actions: things like changing recruitment practices I think was the most common. Only around 10% or 15% of organisations were doing that as a result of signing up to Disability Confident. There are lots of Disability Confident organisations, including Disability Confident leaders, who say they have not hired a single disabled person as a result of signing up to Disability Confident.

I think the intention of Disability Confident is right. It shines a light on the biggest problem, employer attitudes, but there just does not seem to be enough within that scheme to make the difference that it should, particularly given the emphasis that the Government put on Disability Confident as part of the way in which they would close the disability employment gap.

Daniel Jennings: I would echo a lot of what Rob said. In fact, I think there are only about 20,000 employers signed up to Disability Confident. The commitments do not go far enough, and the Disability Confident commitments are what we would expect any good employer to be doing. You can reach the highest level of Disability Confident without having hired a single disabled person. That should be a given to get to the highest level of Disability Confident.

We would like to see those commitments strengthened significantly. That would help to improve the overall vision of Disability Confident and would hopefully encourage more employers to sign up to it. At the moment the take-up is quite low. It needs to be communicated more and the benefits of it need to be communicated more to small and medium-sized enterprises.

Martin Sigsworth: I think Disability Confident, while well-intentioned, is not providing employers with the information that they need to be confident in employing disabled people. Also, I do not think that the scheme is particularly great at linking employers with organisations like TPT.

I have carried out training with Disability Confident leaders, which we have approached off our own back, and have spent a full half-day explaining the assistive tech that a blind and partially sighted person can use within their workplace. These people are Disability Confident leaders, and as members of staff, this was new information to them. There is definitely some sort of breakdown between somebody becoming a Disability Confident leader and that information of how they can support different disabilities being passed on through our members of staff within that organisation.

Q179 **Dr Spencer:** We have heard a bit on this panel and the previous panel about how one of the metrics of success of Disability Confident should be that someone with a disability has been recruited. Is there a danger that, if this was brought in in terms of one of the measurable outcomes, that might disincentivise some companies from getting involved? At the end of the day, if they end up not employing someone with a disability, for whatever reason, they might be scrutinised for not having done so. What is your take on any unintended consequences of using that as a metric of success?

Rob Geaney: I understand the point and I understand the barriers of entry to the scheme for the committed levels, so the bottom of the three levels is so low. The issue we have is that any organisation that has committed is able to display the Disability Confident logo. I think that gives the wrong impression. If you are going to have a very low barrier to entry there should be a bit more scrutiny of who can claim to be a Disability Confident employer. Those committed employers do not do the things that we would expect a Disability Confident employer to do and they certainly do not do the things that a member of the Two Ticks scheme—which Disability Confident has largely replaced—would undertake.

If you want very low barriers of entry at the entry point to the scheme, you need to make sure that that is not allowing employers to give false impressions to prospective members of staff.

Martin Sigsworth: I would say that that would have to be one metric in a series of metrics that Disability Confident employers would have to report on. It would be important to go, "Look, we know that there is X amount of disabled people" and maybe not every single employer who is Disability Confident at that point or in that year or that reporting year will have recruited somebody who is disabled, but if they can confidently say, "but we have had our recruitment process looked at by a sight loss organisation, looking at our perspective, and we know that our recruitment process, our online application process is accessible", that is as important as that overall metric that you are saying of a disabled person getting a job.

If an employee can demonstrate that the opportunities for disabled people to get employed within that organisation are there and that has been demonstrated as part of Disability Confident, from my perspective, that is as important as if they are getting a disabled person into work. That has obviously always got to be the end goal, but it is not the only determining factor of whether an employer can say that they are Disability Confident. As I said earlier, if a blind or partially sighted person cannot fill out their application form online—and I have seen examples of this with Disability Confident leaders—how can they say they are a Disability Confident leader when a blind or partially sighted person cannot complete an application form? That one metric that you mentioned is important, but there needs to be other ones in place as well.

Dr Ben Spencer: I am not trying to put words in your mouth, but from what I am hearing some of the problem is the self-certification nature of the scheme is problematic and there needs to be—I see yes, everyone is nodding—an objective assessor, in a sense, for it to work better. Okay, that is great. I am conscious of time. I will hand back over to the Chair.

Chair: Thank you very much. That completes our questions to you. Thank you all very much for joining us this morning and for the very helpful answers you have given us, which we will certainly draw on as we move to putting together the conclusions from our inquiry. Thank you.

Examination of witnesses

Witnesses: Sarah Rawlings, Catherine Hale and Professor Karen Walker-Bone.

Q180 **Chair:** We welcome the second panel now to join us. Thank you to all of you. I think you have been with us through that first session as well, so you have heard the discussion that we have had. Can I ask each of you very briefly to introduce yourselves?

Sarah Rawlings: Hello, I am Sarah Rawlings. I am the Executive Director of Research and External Affairs at the Multiple Sclerosis Society.

Catherine Hale: Hi, I am Catherine Hale. I am the Founder and Director of Chronic Illness Inclusion, a small disabled people's organisation for people with energy-limiting chronic illness. I am having to do this session here reclining because it helps with my cognitive fatigue and dysfunction, so just to explain that.

Chair: Thank you very much for being with us. Professor Karen Walker-Bone.

Professor Walker-Bone: Good morning, everyone. I am a Professor of Occupational Rheumatology at the University of Southampton. Today I am representing Versus Arthritis, the leading UK charity for people with musculoskeletal disorders. It is a very difficult term to explain, because most people do not know what a musculoskeletal disorder is, but things ranging from arthritis and osteoporosis through to lupus, back pain, fibromyalgia, those sorts of things.

Q181 **Chair:** Thank you. Can I put the first question to all of you? As you will know, the current Government target is to get 1 million more disabled people into work by 2027. The previous target was to halve the disability employment gap. Can I ask each of you which you think is better? What are the strengths and weaknesses of those two different approaches to a target in this area?

Sarah Rawlings: It is important to measure the number of people that are getting into work. However, I think the disability employment gap perhaps provides a better opportunity to look at things like how many people are remaining in work and measure that as well. Many people with multiple sclerosis, for example, have symptoms during the peak of their working lives, and eight in 10 leave or retire within 15 years of their diagnosis.

The disability employment gap, in some research we have done, seems to be bigger than the average, so we are very keen that the Government look at measures that include retention, not just those people that are coming into work. It is also very important to have an impairments group or a condition-specific disability employment gap measure. This is very important, so that we are able to focus support where it is most needed. There are other indicators as well that are very important and should be measured, for example, quality of jobs, disability pay gaps, job satisfaction gaps. Also things like career progression should be measured, which we know is very important to a lot of disabled people, including those with MS.

Catherine Hale: Obviously it is very important for Government to have a target. We do agree that measuring the disability employment gap is a more meaningful measure than trying to get 1 million disabled people into work, because we know that measure could be influenced by how disabled people are reporting disability or not and by demographic changes within society and the labour market.

We also would like to see Government set targets and develop measures for preventing people from falling out of work when they become disabled. As previous speakers have said, we would like to see mandatory reporting by employers of the number of disabled employees and their pay rates in companies of a certain size.

We would like to see the outcomes of the Government's disability employment programmes more transparent and more held to account, the programmes run by private contractors, and particularly for them to be benchmarked against the numbers of disabled people that move into work without these interventions. I would also agree with the previous speaker that it is so important to have good data when looking at the disability employment gap on impairment types. We use the term "energy-limited chronic illness" to group conditions together by their impact, especially their impact on employment.

We know from our research that fatigue or energy limitation is the most predominant feature and the most work-limiting feature among a broad range of conditions, neurological, musculoskeletal, autoimmune as well as obviously ME, fibromyalgia and respiratory diseases and of course we need to think about long Covid, which is affecting 1 million people now and for which fatigue is the predominant feature.

Unfortunately, from the data that the DWP collects in the Family Resources Survey, we know that impairment of stamina, breathing or fatigue affects one in three disabled people, so it is a very broad group of people with a range of conditions that have a similar impact on their ability to work. Unfortunately, in the Labour Force Survey, where the data on the disability employment gap is found, the typology of impairment is different to the Family Resources Survey and there is not that category that looks at energy impairment, stamina and fatigue. Instead it is divided up by which body systems are affected or by diagnosis, which is kind of an outdated medical model way of looking at disability in groups of disabled people.

We would like to see the data collected within the Labour Force Survey to be redesigned, so that it has that broader category of energy-limiting chronic illness so we can see the numbers of people affected in this way and find solutions to help them into work.

Chair: Thank you. That is in the Family Resources Survey, is it?

Catherine Hale: Yes, so within the Family Resources Survey it uses a typology of impairment that is recommended by the Office for National Statistics. One of those categories is impairment of stamina, breathing or fatigue. As I said, it is the third largest group of disabled people of working age, so it is a very important category to use because it tells you about the impact of someone's condition, not just the diagnosis. It is not used with the Labour Force Survey, which we think is a missed opportunity to collect that data and have that bigger picture.

Professor Walker-Bone: I share everybody's view that measuring this gap is vital. There is no question that we are highlighting a very key issue and missing a massive talent pool by excluding disabled people from our workplaces.

What I also want to draw attention to is working is generally good for people's health. Most people with musculoskeletal disorders tell us that they want to work. We know they are financially better off for working, but probably some of their symptoms are better controlled as well by being in the workplace. Of course, financially it is much easier to be earning your own money and to be responsible for how you spend it than to be dependent on the benefit system, so that is all I want to say on that.

Q182 **Dr Spencer:** In passing, I think my line of questioning has been covered, but I want to go back to see if there are any other bits to cover. It is around the quality of the data in terms of people with neurological, musculoskeletal and energy-limiting chronic illnesses in work. I am very interested in your point about focusing on symptoms and impairments rather than the diagnosis itself, which I completely get what you are saying in terms of that, that it is more useful in terms of that disconnect. Are there areas where more data is needed? If so, how are they better collected?

Professor Walker-Bone: One of the areas I would like to see much better data on is from Access to Work. We know it is a very underutilised service. More than 50% of people with musculoskeletal disorders have never heard of it, so it needs better promotion. It has committed to do so, but we need some metrics to understand if it is working, we need some data about who is using it, but also the nature of the conditions and disabilities it is supporting and also whether it is enabling work retention, because at the end of the day that is what it is all for and we have no data to tell us whether it is working.

Sarah Rawlings: I would add that what both Catherine and I have mentioned around impairment specific and condition-specific employment gap measures are very important. It is the way that we are going to be able to tailor employment support better, but also overall figures around disability employment do mask a very heterogeneous group of people with very different challenges and contexts. They will require very tailored solutions, which is why it is so important to kind of move this on so that people do get the support they need, both to access work but to also stay in work.

Catherine Hale: Obviously I have made the point already. What I would like to add is that it would help to have a standardised typology of impairment used across all the different policy areas from social care, employment support to disability benefits. We approve of the one recommended by the Office for National Statistics, which includes this category of impairment of stamina, breathing or fatigue. We would prefer it to be termed energy impairment or energy-limiting chronic illness, because this is closer to how people with lived experience of these conditions would like to describe it or have their conditions understood.

Generally we think that there is a problem that there is a different typology of impairment across different areas and that it should be standardised. It would be much more helpful then to apply the policy solutions across the board.

Q183 **Dr Spencer:** On that point, just in terms of doing it by trying to get a thematic approach to different types of impairment or symptoms, I wonder how that would work in practice. Take my experience in terms of looking after people with psychosis. One of the things that tends not to be picked up and is very difficult to explain is what is known as negative symptoms of schizophrenia, where people are demotivated. Often that can be misinterpreted—when people do not understand or have experience of managing a condition—that people are just being lazy, when it is a part of the illness, apathy and demotivation.

It is how you differentiate it from the different type of fatigue that you see in things like chronic fatigue syndrome, the very different lack of energy that you see in somebody who has chronic depression versus someone who has chronic renal impairment, versus someone who has chronic inflammatory disease driven by arthritis. How does that work in practice, in terms of separating this out and the amount of training in terms of people who would be doing these assessments and needing to understand the detail of a range of symptomatologies for a range of different conditions? Are there any consequences to taking that approach? I would be interested in your thoughts.

Catherine Hale: That is a very, very interesting question. Obviously with fatigue, we use the term "energy impairment" to convey that we are talking about an objective loss of function. There is a problem with the term "fatigue". People feel that it describes a subjective sensation of something that you could push through as opposed to an impairment or a loss of function. Obviously, as you say, within different diseases the biology of fatigue is different, the quality of fatigue is different and that is very important.

It is important to hear from mental health groups on that type of fatigue as well as the type of fatigue in kidney disease and fatigue in long Covid. There will be subtle differences, but we have found from our research that there are also an astonishing number of similarities in the way that this impacts on work capability. That is why we think that it is useful to take this broader focus, so that you do not miss the bigger picture and the kinds of difficulties that people have in work and the solutions that could help them.

Dr Spencer: Thanks, that is very helpful.

Professor Walker-Bone: It is a very important question. You put your finger on it with mental health and MS being great examples of how variable the degree of impairment is. We have been stuck with this word "disability" and this word encompasses people with long-term health conditions, a huge variety of symptoms and yet most people think of it as somebody in a wheelchair. We have seen some fantastic examples today of how variable disability is. If you think about the word, it means of lack of ability, and that is how we should be treating it.

For me, to solve the problem about working, we should be looking at what people can do and making jobs as suitable for their needs as possible. What label we have given the disease, the medicalisation, it is completely unhelpful as far as I am concerned. I think those of us in medicine are probably allowed to say that but sometimes that is unhelpful. It is about the symptomatology, the functional impairments to do what you need to do for that job and it is about having more jobs available that can give the flexibility and understand the needs of the individuals.

We need a culture shift in this country towards jobs that are made for people. All workers need flexible jobs, all workers need to be treated well by their employer, and we should be praising employers who do that well and working towards a country where we offer good jobs that are suitable for the needs of the people doing those jobs.

Sarah Rawlings: Like the previous speakers, I think it is a very important question. Their answers have covered it extremely well. Disability is incredibly variable. Even with multiple sclerosis there are a range of different symptoms. It is an incredibly unpredictable condition that affects each individual in a very different way. We do need that culture shift to better understand different conditions and symptoms that people experience so that we are better able to tailor the support in a very good way.

Q184 **Debbie Abrahams:** Good morning, everyone. I am going to declare an interest. I was diagnosed with severe arthritis at the end of 2016, so I can talk about my own experience within the workplace in Parliament and the support or lack thereof that I received. I am very interested to hear from all of the speakers in terms of what they feel are the barriers to remaining in work and, also, to accessing work for people with neurological, musculoskeletal and energy-limiting chronic conditions. Sarah, do you want to kick off?

Sarah Rawlings: Sure. I think I mentioned in a previous answer to a question that most people with multiple sclerosis experience their symptoms in the peak of their working lives and eight in 10 will retire or leave within 15 years of their diagnosis. The condition is very different and unpredictable for everyone but in many cases, with the right support and a supportive employer, people can remain in work.

Often the root of the problem is around a lack of understanding. For instance, as we heard in the previous session, many employers do want to do the right thing but they may not know enough about how they can support their employee, including the support schemes that may be available to them or the reasonable adjustments that they may need to be made and can be put in place.

Last week was MS awareness week, so we are very keen to push this point around the importance of awareness and understanding of the impact of MS, what support can be provided to employees, but also what support is available to the employer as well. Unfortunately, people with MS do not always work in an environment where they feel that they can raise this awareness themselves.

We undertook a recent survey around talking about MS and a quarter of people felt least confident talking about how it impacts on their work: 33% said they kept their MS a secret from their employer, 40% said they kept their MS from their employer because they were worried about how it would affect their career, and a similar number kept it from their employer because they were worried about discrimination, so this awareness point is incredibly important.

However, there are also wider societal challenges that prevent people from getting into and also staying work. For example, people with multiple sclerosis and other health conditions rely on other means of support as well. It could be from the social care system to enable them to get up and get ready for work in the morning. If we do not have these types of things in place as well, access to accessible transport and so on, we are struggling to help people to both access work and remain in work as well.

Catherine Hale: Our research has found that with the barriers to work, there is a kind of complex interaction between health factors and social barriers. It is important to spell out the health factors with energy-limiting chronic illness because they are so often disbelieved, misunderstood and dismissed. Energy impairment, as we said, is different from the universal experience of fatigue. It means that if you have a very limited amount of energy, just the acts of washing and dressing might mean that you have no energy left to travel to work, let alone get through a working day.

Overall, energy impairment limits the amount of work people can do more than the type of work people can do. This is so important to get across, that we are talking about limitation in the number of hours people can do in any week reliably and repeatedly. Cognitive fatigue is probably the most overlooked aspect of energy-limited chronic illness. We are talking about brain fog and loss of function, such as concentration issues, short-term memory, communication, and again about the duration of concentration people can sustain.

This is possibly the most significant issue in relation to work. Fluctuation is something that there has been awareness of and obviously it is a huge barrier to work if you cannot predict when you are going to be able to perform in the workplace, when you are going to be available. That has a massive knock-on effect on an organisation that needs to align deadlines and targets. As an individual, if you cannot fulfil those targets that is obviously a big barrier to employability.

In terms of structural barriers from within the labour market, there is a lack of suitable jobs to match with people's capacities. So many people with energy-limiting chronic illness would love to have a job that was less than 16 hours a week, for example, because that is all that they would be able to give in terms of energy to employment, but there are so little job offers in place that go beyond the standard full-time or even the standard part-time hours for people with limited hours of work.

Management styles within work we found are very important and can be either enabling or disabling. When presence in the workplace and hours are given more importance than performance and output, that puts huge barriers in place to people having the flexibility they need to manage a fluctuating condition and get adjustments like working from home or reducing their hours.

As other previous speakers have said, lack of awareness and understanding of energy-limiting chronic illness and energy impairment, as well as being a form of hidden impairment, alongside which people face the stigma of disbelief. We found that in our research there is often a huge barrier to even disclosing disability in the workplace because fatigue is so often dismissed as a universal thing and that you just have to pull yourself together, "Push through, don't be lazy". So it takes a very long time for people to feel they are even entitled to identify as disabled.

Then there is the lack of understanding among employers, so negotiating the adjustments that they may need to remain in work, the barriers to achieving that mean that so many people are falling out of the workplace when they acquire an energy-limited chronic illness because they don't have the confidence and there is not the employer awareness to negotiate those adjustments that may have kept them in work.

Debbie Abrahams: That is very comprehensive. Thank you very much.

Professor Walker-Bone: Debbie, thank you for sharing your story and I am very sorry to hear about your experiences. As you know yourself, the main problems with having a musculoskeletal condition are pain, fatigue, mobility and stamina, as we have been hearing, and also needing time off for treatment and diagnosis and all the various appointments that we make you have and blood monitoring and all the rest of it.

What most people are telling us is that they find their employer poorly equipped to give them the flexibility that they need. Particularly in the early phases of diagnosis of an inflammatory condition, you need a lot of appointments and a lot of monitoring but the prognosis can be really good. However, with the employers—on their fixed system of, "After your three months of not coming in, I'm going to tell you off, and after six months I'm going to think about making you redundant"—there is not that understanding that time would enable you to be back to normal.

I have to say, I have been listening to all the different speakers this morning thinking about the nature of all the different impairments that people can have. If you are an employer of 20 people and suddenly you have someone who has sight loss, hearing loss or arthritis, we are expecting an awful lot of them. What is coming to me is that we must give people better support to enable them to support their employees—dare I say it—even some kind of incentivisation, because this is hard. How are they going to know?

One of my stories was of a porter working in a hospital who took his mother every day for her chemotherapy during her last illness. On the last day, the day she died, he rang in and said, "I don't think I can come in today". His line manager said, "All right then, but you better be in tomorrow". Line managers for porters in hospitals are not highly qualified. They are not very empathic. They have a role that they do not really understand and they feel they have to meet their targets, which is what it is all about. We understand that. We really need a different way of doing this.

Q185 **Debbie Abrahams:** Thank you so much, Karen. Could you build on that by identifying the barriers? You have started to identify potential solutions and also the issues that employers face. What more do you think that employers—recognising the different types of employers and the different sizes of employers—could do to keep people in work and then, as I say, also to encourage people with these conditions into work?

Professor Walker-Bone: Thank you. The main thing to point out here is that we know, certainly with musculoskeletal conditions, the nearer to the workplace you are the more likely we will be able to get you back to work. If someone has been off for six months with back pain they have a 50% chance of ever working again, and after a year it drops away to less than 20%.

At the moment, it seems to me that we have put a lot of resource into the people who have been out of the workplace for two years or more rather than, as has been mentioned by many other speakers, investing in retaining them in the workplace or close to the workplace while we support them through their diagnosis phase and they are getting their management better established phase.

This is hard. I think Access to Work has the right principles at stake but it needs a bigger voice. It needs to be better monitored. It needs to be better promoted and it needs to become the authoritative place that employers can go to. This idea of an online hub, let us link it all to Access to Work. Let us make it possible for us to see who is accessing the help, why they are not accessing the help, which kinds of conditions it is catering well for and which ones it is not, and then how we can improve it going forward.

Catherine Hale: Obviously the Equality Act, which places a duty on employers to make reasonable adjustments, is probably the key lever that is already in place to support and retain people in employment. Reasonable adjustments are often perceived as being about changes to the physical environment or expensive pieces of equipment. However, with energy-limiting chronic illness the most effective adjustments that people need to remain in work are changes to the timing of work—as we said reduction in hours, changes to the pace of work so they are given more flexibility to complete tasks and managing a fluctuating condition and completing tasks in the timeframe that works for them—and also in the place of work.

Working from home is a huge adjustment that enables many people with energy-limiting chronic illness to work. Often before the pandemic, when people asked for this adjustment, they were told, "No, it's not possible. We cannot have you working from home. It doesn't work." We have seen through the pandemic that within a matter of weeks the whole nation was working from home, it was absolutely doable and the technology is there for remote working. It is a good news story, because reasonable adjustments are about working from home, having more control over your hours, flexible work. There is just a lack of awareness among employers that that is sometimes just what it takes to keep disabled people in work.

We do need better mechanisms to enforce the Equality Act because at the moment the onus is all on the individual. It is an enormous burden when you are in a conflictual relationship with an employer to take it to that stage. Therefore, we would like to see better mechanisms to enforce the duty for reasonable adjustments.

Education and training on energy-limiting chronic illness is needed across the board for managers so that they understand the difference between normal everyday tiredness, and fatigue and energy impairment and all the features that are associated—the cognitive fatigue, the fluctuations and the paybacks so that for every activity that you do there is a recuperation time that is needed—so that they are able to support employees with the right adjustments.

I think, agreeing with what other speakers have said, Access to Work is hugely important. I believe only 25% of employers were aware of it in a survey by the Centre for Social Justice. Therefore, promoting awareness of Access to Work among employers would mean that they were able to get that support in place for their employees and work together on the process.

Something we might come to later is: we think there is a really important role for Government to promote job creation of certain types, or niche types of jobs, for people with chronic illness. Perhaps I will speak a bit more about that later when we come to commissioning employment support.

Sarah Rawlings: I very much agree with what has been said. A key theme that is coming through is around information and support for employers. We are very keen on this one-stop shop and this information hub idea. If we could provide all the information in one place that is easy to access it will be all the information that people need. For example, understanding legal duties under the Equality Act, understanding what reasonable adjustments can be made and that it does not have to cost a lot of money sometimes, and that Access to Work does exist. That is really, really important.

We would also like, as has been mentioned as well, improvements to schemes such as Access to Work, both in how it is publicised so that people know about it but also when and how it is used. For example, it being available earlier than when you are actually in a role because it can take some time for reasonable adjustments to then come into play. Also the fact that came up in the previous session as well, which is that you cannot take your Access to Work to another job if you move jobs. You have to go through the process again. Some tweaks like that or changes like that could make a real difference in both the confidence of the employee and the employer, and could make a huge difference in getting people into work or to remain in work as well.

Q186 **Debbie Abrahams:** I think we meshed a little bit with the final question that I was going to ask, so perhaps if we can just limit it to one thing.

In relation to what Government can do, particularly the Department for Work and Pensions, could you all mention one thing—whether it is a new policy, whether it is amplifying an existing policy or programme or whether it is in relation to employment support—what more we need to do to help people with these conditions remain in work, which can be done by these Departments?

Professor Walker-Bone: What I think I would like is to see the DWP working more closely with DHSC and more closely with BEIS so we have a joined-up approach to how we are going to manage this. It cannot do it on its own. It is basically picking it up when it has all gone wrong, it is too late. When a health condition has been diagnosed, or indeed when health symptoms are presenting, we need for care and support to be put in place and for the management to be trained and supported to help.

Debbie Abrahams: Very helpful. Thank you, Karen.

Catherine Hale: Yes, it is really difficult to choose just one thing. As other speakers have said, the integration of Access to Work with other forms of employment support is absolutely crucial.

One thing I would like to flag up is that we would like to see Government and contractors more involved in job brokering and job creation, supporting employers to tailor their job offers and to create niche roles that may be less than 16 hours a week and may have the flexibility and the working-from-home provision that would cut out some of the unnecessary duties from a standardised job role. There is what we call an invisible talent pool of people with chronic illness who would love to work if the right kind of role was available. Job carving is something that is known in relation to learning disabilities and works effectively. Agencies are needed to work with employers to carve out those roles. We think that is a really important solution for people with energy-limiting chronic illness.

Sarah Rawlings: It is very, very difficult to choose just one thing. We have all spoken about a range of different options and possibilities today.

I would like to add in the importance of tailoring what is provided and also ensuring that what we provide is also person-centred. A lot of that is to do with working very closely with disabled people on the schemes that are in place and what is being discussed. That is absolutely integral to ensure that we really do get this right.

Q187 **Steve McCabe:** Good morning. I want to ask specifically about local employment support. Can I start with Sarah? I note that the MS Society is a keen advocate of localised employment support, I think you said delivered by local authorities and charities, which you say would deliver better employment outcomes for disabled people. I know there is quite a lot of support for that view. However, my own understanding is that the evidence for the claim is a bit thin. How did you come to this view and what do you think the benefits are, Sarah?

Sarah Rawlings: Absolutely. What we hear from people with and affected by multiple sclerosis is that a one-size-fits-all approach does not work. There is perhaps more of an opportunity to build a local, more holistic, model to support people with MS to find quality work and to remain in work.

When we are thinking about that, it is how local agencies can work together to tackle various barriers that people have to employment. That could include things such as access to inclusive transport and the social care support that I raised earlier as well. There is perhaps more of an opportunity to engage with disabled people for their own views and experiences at a local level. Also, support delivered by local providers can perhaps provide an opportunity for understanding of the local employment market. That can build really meaningful relationships with employers so we know who is out there, who really wants to work and is keen to do so.

The disability strategy actually provides a very good opportunity for us to ensure that employment support is holistic and tackles the various barriers that exist for disabled people. Our approach is that we are keen to ensure that there is not a postcode lottery. If we can tie up these local agencies working together, the experience for the disabled person may be improved than if things are always dealt with at a national level.

Q188 **Steve McCabe:** Thank you. Karen, does your organisation take the same view?

Professor Walker-Bone: That is a really hard one. I can see a huge advantage to joining up transport, housing, social care and health care with employment and I can see that being a really good way forward. However, then I started to think about health inequalities. We know there are patches of the country where—Covid has just shown us all, hasn't it—we have people who are much more vulnerable, with lower educational attainment and there are poorer jobs in their areas. Is it going to widen health inequalities if we have everything locally provided? It would have to be ring-fenced funding that genuinely went to the needy. I do not know how you do that on a fair basis across the nation but that would aspirationally be really good.

Q189 **Steve McCabe:** That is helpful, thank you. Catherine, does your project take a view on this issue of national commissioning versus localised support?

Catherine Hale: Yes. For us the division is not so much local versus national, it is a division between small not-for-profit specialist organisations that have that impairment-specific knowledge and the larger national contractors that work in a more pan-disability, one-size-fits-all kind of way.

The organisations that we would like to promote are small not-for-profit organisations and services that are specifically geared to people with chronic illness. An example is Astriid, which is the only charity of its kind in the UK that matches people with chronic illness with employers, and it fulfils that job-brokering service that I was talking about earlier. It supports employers to tailor their job offers, to create specialised roles and to understand the needs of people with chronic illness, as well as supporting people with chronic illness to move closer to work.

Chronic Consulting is another service. It is a start-up organisation that coaches people with chronic illness, supporting them with disability disclosure and with awareness of reasonable adjustments, and helps them to negotiate reasonable adjustments with their employer.

Both of these are examples where they are not geographically local but they are small and they are specialised. At the moment they are locked out of the commissioning models that the Department uses to commission disability employment support. Therefore, their funding models are insecure and unsustainable because they are locked out of that commissioning system, which favours the large national contractors.

For me, it is not about being geographically local but it is about having the specialist knowledge, coming from the voluntary community sector and being locked out of the commissioning cycle by their small scale.

Steve McCabe: That is very helpful, thank you very much.

Q190 **Siobhan Baillie:** Thank you, everyone, for joining us. This is specifically to Professor Walker-Bone. You have said that the application process for Access to Work can act as a barrier to disabled people seeking support. Other disability organisations have also described the application as being bureaucratic and really time consuming. I would like to know a lot more about what the Department should be doing to fix the scheme and fix those problems.

Professor Walker-Bone: Thank you, Siobhan. It is interesting, they have responded to the pandemic in a very constructive way and hopefully the more hybrid way of working could be a way forward for the future. We all know that DWP is under enormous pressure. I imagine the providers of the Access to Work service are not necessarily hugely well paid and hugely well-resourced themselves. They are just too far stretched. They do not mean for there to be delays; they do not want delays. They are slow to answer their phone. They are slow to answer their emails. Things take a long time from the perspective of the individual trying to get the support.

Q191 **Siobhan Baillie:** I have another question, moving on, for everybody. The Government plans to publish the National Strategy for Disabled People, they are working on that at the moment, and a Green Paper on health and disability support. What would you like to see in those papers as a priority?

Catherine Hale: Yes, we would like to see them consider people with energy-limiting chronic illness as a large group of disabled people with their own set of needs and specific sets of policy solutions. We have been disappointed that the process of the consultation itself has been really inadequate. There has not been, for example, enough time given for disabled people to respond to the survey that they put out, which is really disappointing. There has not been enough engagement, or I do not think any engagement at all, with disabled people’s organisations led by disabled people themselves. There has not been engagement with disabled people’s organisations for people with energy-limiting chronic illness.

The process itself has been disappointing. We would like to see a focus, with this particular impairment group—stamina, breathing and fatigue—seen as a coherent and large group of disabled people because it has previously been invisible and ignored as a group.

Q192 **Chair:** Sorry, Siobhan. Catherine, could you make your job creation point here, just to make sure we do not lose that, the point you mentioned a few minutes ago.

Catherine Hale: Yes, absolutely. We would like to see the Government work with the smaller employment support providers, such as Astriid, which have specialist knowledge and are able to work on the area of job creation. In the same way as job carving is a strategy used with learning disabilities, we think it is a really important strategy to use for people with chronic illness. We need to look at the job offers that are available in the labour market and how they can be tailored, adapted and redesigned so they are more suitable for people who can only work reduced hours, who need particularly flexible hours, who need high levels of autonomy in the workplace and who need provision to work from home. Hopefully that could be a big part of the strategy.

Q193 **Siobhan Baillie:** That would be an improvement of engagement if, for example, the Government were to speak to Astriid.

What else would good engagement look like to you, if we were starting the strategy again and if the Government wanted to do more engagement with disabled people now?

Catherine Hale: Chronic Illness Inclusion is a recently constituted disabled people’s organisation and we would be really, really happy to meet with the Government developing this strategy and to talk more about our work, our research. We have really good engagement with our supporters, a very, very active group. When we put out surveys and consultations among our supporters we get huge volumes in reply. We have a very active membership, if you like, and we would be really willing to meet with Government to share our work.

Q194 **Siobhan Baillie:** The same questions to Sarah first and then Karen; what you hope to see in the strategy and also what good engagement looks like for future consultation.

Sarah Rawlings: Absolutely. The strategy in the Green Paper actually provides a real opportunity for change that it would be fantastic to grasp. It will be interesting to think about how every Government Department can ensure their policies are inclusive for disabled people as well. This issue does not sit just within one Government Department.

We would like the strategy to take a very broad look at the challenges disabled people face. There are some really important issues within there, which have come out in previous sessions held, such as tackling and reducing poverty among disabled people. That is a real issue and must be one of the priorities.

Some of the other issues we think it should include are, for example, better financial support for disabled people, both in and out of work. The starting point there would be to give legacy benefits the £20 uplift that was given to Universal Credit claimants at the start of the pandemic.

Things like access to inclusive transport, better provision of accessible housing, a social care system that supports the needs of disabled working adults.

We know with multiple sclerosis one in three people say they do not have the social care support they need. That is often quite important around employment as well. For example, you may need support, as I have mentioned previously, to actually get up and ready for work in the morning. More generally, measures that can help improve social attitudes to disabilities. We talked a lot today around awareness and around supporting employers. The more that we can talk about these issues and why it is really, really important the better.

In terms of engagement with disabled people, there is much more that can be done. It is also really important to remember that there is a variety of methods needed and not just to rely on one form of consultation or one survey. As came out in the previous session today, there are lots of adjustments that need to be made, and also digital will work for some people and it will not work for others. We really need to think about what is best to meaningfully engaged with disabled people in these really important areas.

Professor Walker-Bone: I will try not to be repetitive. I would like to see a really clear definition of who is disabled, what disability is. I do not know what Debbie would say to this but most of my patients with arthritis do not perceive they are disabled. If you read the disability definition in the Act they are, but they do not think of themselves as disabled.

I also think it would be really nice to see a better definition of what reasonable adjustments look like from the perspective of different types of impairments, so that employers are clear on what the minimum is they should be providing as a reasonable adjustment.

Engagement is absolutely key. It needs to be engagement with people with mental health conditions, musculoskeletal conditions, the whole range of different types of impairments, so that we get a real feeling that any policy made, any strategy devised, is led by them and they told us what would work for them.

We need better data. We really do need to clarify what we are going to collect in order to show any progress from the strategy, what are our targets, have we met them and when are we going to evaluate that.

I absolutely urge the importance of the strategy being nested across Departments. It cannot just be one Department; this has to be around local government.

For young people with chronic disabling conditions—epilepsy, mental ill health, autism or arthritis—they need to have a chance of getting a job. We really need to improve the career planning for them and give them much better support through Access to Work to make sure they get in the workplace.

I could not reiterate more strongly Sarah's point about why we are leaving our disabled people in poverty. This is wrong.

Q195 **Chris Stephens:** Welcome to the panellists. Following on from Siobhan's question, and thinking about the role of Jobcentre Plus itself, what improvements can the Department make to the support it offers to unemployed disabled people?

Catherine Hale: Thank you. We have heard that there are more disability employment advisers coming on board. However, in the context of what has happened through the pandemic, and that there are I think 25,000 more work coaches being put in place, the number of disability employment advisers is still much too small in proportion to the number of work coaches.

We need work coaches to have impairment-specific knowledge so they can apply solutions that are not one-size-fits-all but according to people's support needs. We want to see more disability employment advisers within job centres, having impairment-specific knowledge and specifically around energy impairment obviously. In terms of work coaches, for them to apply a personalised approach and especially applying conditionality in a personalised way. They need to understand the issue that with energy-limiting chronic illness it is about the number of hours you can do rather than the type of work you can do.

That is hugely important when it comes to in-work conditionality under Universal Credit. We have a real concern that if people are able to work just a few hours a week they are going to come under pressure to increase their hours because there is that inbuilt assumption in Universal Credit that you need to progress from part-time into fulltime work, which is completely inappropriate for people with energy impairment.

In order for work coaches to apply conditionality in a personalised way and in a way that is not going to put people under pressure and create more stress, we need that impairment-specific knowledge across job centres, so more specialism and more investment in disability employment advisers.

Q196 **Chris Stephens:** Thanks, Catherine. I note your comments on the disability employment advisers, so thanks for answering that.

Sarah, are there also things that DWP can do to improve employers' knowledge?

Sarah Rawlings: When we ran a survey and asked people with multiple sclerosis in the past 12 months, "Have you received support to help you find employment?" 61% of those people said, "No, but I needed support". Also, people with MS have told us that they actually avoid applying for benefits to avoid having to deal with the Jobcentre, so there is much more that we need to do there.

I do not want to repeat what Catherine has said, but I do agree with her points around much better understanding among work coaches, the need for disability employment advisers, and actually how that system works really well to provide the support that is needed so more people feel confident in accessing that support as well.

Professor Walker-Bone: Callers to Versus Arthritis tell us that they have a real problem with Jobcentre Plus as the sort of poacher/gamekeeper role. They are there for the gatekeeping of the benefits and then you are supposed to go to them for help and support to remain in work. They have a real fear of what information is being transferred. Therefore one wonders if it is the best placement of our work advisers, our work coaches, or whether we should be linking that more with Access to Work and separating it off from the benefit system. That is certainly something that needs thinking through because it is not helping people at the moment; they are fearful of going, fearful of full disclosure.

In terms of what managers need, we talked about knowledge and skills. I think actually it is a leadership culture from the top. If your manager is on your back because your productivity has dropped you are not going to be very empathic to the person you are trying to support with a health issue, so we need a whole culture shift in the organisation.

It is worth noting—no one has said it so far—that we have dropped the capacity for occupational health in most of our businesses in this country. Less than half of people in the UK have access to any occupational health so they are either turning to a specialist or their GP. GPs tell us they do not want to do this; they think it gets in the way of what they do. We do need to think about whether a telephone call provided by a commercial provider of OH services, usually someone not a doctor or a nurse, is really a substitute for good occupational health support in the workplace.

Chris Stephens: Thanks very much, excellent answers.

Q197 **Selaine Saxby:** The question I have here I think you have just touched on, so in the interests of time if we can just focus on any additional information you would like to add.

In your view, how well is the benefit system achieving its aim of supporting disabled people into work? As we know, DWP's view is that the conditionality and sanctions regime acts as a work incentive. In your view, what impact is that having on supporting the people you represent into work?

Professor Walker-Bone: We all know that it is horrible. I am lucky enough to talk to patients in clinic and they tell me their experiences of the system. It is punitive and unpleasant and they feel denigrated and stigmatised by it. I know it is a really tough job. I feel really sorry for the assessors, I would hate to be in their job, but many of them are not qualified in any medical discipline or allied health profession. The basic answer is, "No, you cannot have" and you have to appeal and then it is, "Maybe you can have". It is horrible.

Sarah Rawlings: To talk about multiple sclerosis for a second, the majority of people with MS who claim Employment Support Allowance, for example, are placed in a support group and have no working requirement conditionality attached to their benefit. That is good but a small number with MS in this group actually do want to do some work, for example some freelance work that they can fit in around their condition. There is a real reluctance to do this because of the fear of losing their benefit. That is a theme that we hear quite a lot, if you change one thing, there is a real fear you will lose something and lose out.

I want to go back to Karen's point as well on the conversations around employment support and financial support probably need to be separated. It is not particularly helpful and it is causing issues. My understanding as well is that it is incredibly difficult and a quite stressful situation for people when they are claiming for benefits. Conditionality and sanctions for people claiming ESA, for example; are they helping or should they be scrapped? My understanding is that there is no clear evidence to suggest that conditionality and sanctions help disabled people to re-enter work and stay in work: some evidence has emerged that the opposite actually may be true.

Catherine Hale: I concur with what everyone has said. The reliance on conditionality and sanctions as a tool for getting disabled people into work has completely backfired and taken so many people backwards. I had the experience of being sanctioned myself while I was on ESA, which was horrific and added a mental health condition on top of my physical health condition. It has resulted in people not trusting Jobcentre Plus and not trusting work coaches. I agree with what the other speakers have said, employment support needs to move closer to Access to Work and away from the gatekeeping role.

We also really need to address the adequacy of benefit rates as well as the security of the benefit system. The benefit rates in general are among the lowest in the OECD. We need to remember that disabled people on legacy benefits, like ESA, have been left out of the £20 uplift to Universal Credit so people are trying to survive on rates of benefit that are not meeting their basic needs, certainly not allowing them to participate in society and so not giving them a platform from which they can manage their health condition and take a positive approach to managing some kind of return to work.

The insecurity of the benefit system, the flaws in the assessments, the onerous process of appeals and the frequency of reassessments mean people are living on a kind of constant treadmill of anxiety about losing the little that they have in terms of benefits. Again, that is not a place from which people can improve their lives or fulfil their aspirations because people do aspire to a better life and to working if that is possible for them. Putting them in this place of deprivation, anxiety and insecurity is putting people backwards and it really needs to be addressed.

Q198 **Nigel Mills:** This, I think, follows on from some of the earlier comments. What is the panel's view on the Work Capability Assessment, how that works and whether it is a useful tool for determining eligibility for financial support? Perhaps we could find a better way of linking the assessment through to what support people need to get into work and to stay in work, rather than just doing an assessment and then not really using any of the information for perhaps more useful purpose afterwards.

Sarah Rawlings: People with MS have continually raised with us significant concerns about the accuracy and the quality of the Work Capability Assessment. There probably does need to be significant change and improvement to it.

Perhaps now is the opportunity to do that, with the long-awaited Green Paper. We would really urge the Government to take that opportunity and look at designing a new assessment, which includes descriptors and underpinning principles that are appropriate and that also recognises some of the issues that we have been talking about today around how conditions are very different and they are often different day to day for an individual as well. How do we build that kind of recognition in?

I would also like to flag, again, the importance of actually involving disabled people and disabled people's organisations in looking at the assessment and looking at how it could be redesigned. That is so important.

Catherine Hale: We agree, we would like to see the Work Capability Assessment completely redesigned. In particular we would like to see it have an indicator so it can measure the number of hours that people can work in any one week reliably and sustainably. This is done in other countries; it is part of the measurement of how close people are to the labour market. At the moment, the WCA only assesses different functions in isolation to each other but it gives you no way of differentiating someone who can work five hours a week from someone who can work 35 hours a week, which is obviously a key measure of employability that the WCA has no way of measuring.

We would like it to be much more robust in accounting for cognitive fatigue and dysfunction. For example, with long Covid 85% of people say that cognitive dysfunction is the key work-limiting disability. Yet the descriptors in the WCA that apply to cognitive, intellectual and mental function are never applied to energy-limiting chronic illness because they are only applied to people with specific diagnoses, like brain injury and learning disability. This is a wrong approach, which uses diagnosis first rather than impairment and impact.

We would like it to be able to take a more holistic look at people's lives and how they have to account for their energy and allocate it, rather than looking at different activities in isolation from each other. You might be able to do activity X, Y and Z, for example, if you have chronic illness. However, once you have done one of them you cannot do the other two in any one day so you need to have a relational approach that looks at how you can do activities in relation to other activities because that gives a more accurate picture of how much energy people have to allocate to work.

Yes, we would like to see those three things built into a new design for assessments.

Professor Walker-Bone: I do not understand it, Nigel, if I am really honest. I look after a 58-year-old lady with rheumatoid arthritis and HIV. She adopted her grandchildren who are 10 and 13. The 13 year-old has severe autism. Her arthritis is bad. She applied to the WCA and she got completely turned down so she has just taken an extra 12 hours of care work so she can support her family. It is just wrong, Nigel.

Q199 **Nigel Mills:** Yes, it does sound like a strange outcome. None of you said that you think there is no role for capability assessment in this process, what you want is for the assessment to work properly. Is that a fair summary?

Professor Walker-Bone: Yes, I would say the qualification of the people doing it and the criteria against which they are judging are very punitive.

Q200 **Nigel Mills:** No one thinks we could just rely on what the GPs or specialists say, as we do have some kind of independent assessment?

Professor Walker-Bone: We did do that in the past. I have written many of those forms in my life, as I am sure Ben has. Of course, we are advocates for our patients so it does not feel right that it should be the medic making the assessment. It has to be something in the middle between these two extremes.

Q201 **Nigel Mills:** Would it help if the outcome of the assessment was, "We think this person can work for 16 hours if there is this adaptation and there is this support available", if that fed through and that adaptation and that support was then on their file and was advised to employers, if the system was joined up rather than it being assumed for one thing and then forgotten about for the rest?

Professor Walker-Bone: Could not agree more.

Catherine Hale: Yes, I absolutely agree. At the moment it is completely disjointed. The WCA is disjointed from employment support and it is disjointed from Access to Work. What we want is an assessment that, as you say, accounts for hours of work and also, crucially, what support people need, the availability of that support and then gives that person an indication that that support will be available—for example, from

Access to Work—and that type of job is available and exists within the labour market.

At the moment it is a purely theoretical exercise that looks at whether you can pick up a pound coin and then reach into your top pocket. Where are the jobs where you just need to pick up a pound coin and reach into your top pocket? It needs to be much more grounded in the real world of what job offers are available, what support is available. Yes, I agree with the approach that you have suggested there.

Sarah Rawlings: It is currently an inadequate process that leads to stress and anxiety for a lot of people. In some cases people are actually not receiving the financial support they need. Absolutely, yes, more joined up and, as Catherine said, grounded in the real world.

Chair: That concludes our questions. Thank you all very much indeed. I found that a very interesting and useful session. We are grateful to all of you, thank you for being with us. If there is anything else that occurs to you after the session that you think we ought to know about please do email, we will be interested in any follow-up thoughts you have.